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ABSTRACT

This report from the Select Committee on Aging examines financial, medical, and social issues surrounding terminally ill patients with special emphasis on the elderly terminally ill. The first section discusses topics related to the medical treatment of the terminally ill. Two basic issues are important: the right to have medical treatment and the right to refuse medical treatment. Considerations of ethics, competency, surrogate decision-making, advanced directives, and conflicting interest involved in medical treatment of the terminally ill are discussed. This report issues a call for action to policymakers to relieve financial pressures on the terminally ill, foster mechanisms for advanced directives, protect treatment rights of the terminally ill, and to affirm a patient "bill of rights." The second section of the report is by the Congressional Office of Technology Assessment. It examines issues related to five medical interventions including renal dialysis, mechanical ventilation, nutritional support therapy, resuscitation, and the use of antibiotics in the elderly. (ABL)

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[COMMITTEE PRINT]

DYING WITH DIGNITY: DIFFICULT TIMES, DIFFICULT CHOICES

A REPORT

PRESENTED BY

THE CHAIRMAN

OF THE

SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

FIRST SESSION

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In America today, medical technology has given us a much greater ability to sustain life than in the past. Unfortunately, this same technology has created very difficult choices for dying persons, their families, their physicians and society as a whole. America's terminally ill have been placed in a tragic "Catch-22."

On the one hand, national policymakers continue to cite the high cost of caring for the dying. Some have implied that the dying have a duty to die and make way for the living. On the other hand, medical science is becoming increasingly successful at keeping dying persons alive. Physicians face a dilemma as they fight to keep the dying person alive while also trying to deal with the dying patient's decision to have or to refuse medical treatment.

Tragically, the dying person, whether they choose to have medical treatment or to refuse medical treatment, is caught in the middle. This "Catch-22" situation was presented most eloquently in the Committee's October 1st hearing by former Senator Jacob Javits and Dr. Edward Viner, both of whom have faced the tragedy of a critical or terminal illness.

However, describing the problem is not enough. We must act to solve the problem. We must act to reduce the pressure on America's terminally ill and their families.

As stated in the following report, now is the time for federal and state governments to relieve the cost-related pressures on terminally ill persons and to give them the legal vehicles they need to adequately control their final days. Now is the time for everyone, including physicians and other health care providers, to be more sensitive to and supportive of the final wishes of America's terminally ill.

Edward R. Roybal
Chairman

FOREWORD

This report is being released to the House Select Committee on Aging, the House of Representatives and to the public. It describes the dilemma facing America's terminally ill persons and calls for federal and state action to better assist the terminally ill.

Taken together, this report and the Committee's October 1st hearing, "Dying With Dignity: Difficult Times, Difficult Choices," are a critical first step in making the Congress and the public aware of the dilemma faced by terminally ill persons and their families. However, awareness of the dilemma is not enough.

The second step, as outlined below, is to analyze the research and knowledge on the terminally ill and to explore options for dealing with the issues surrounding the terminally ill and their care. In this regard, the two upcoming analyses by the Office of Technology Assessment, prepared at the request of the Committee on Aging and other House and Senate Committees, will be two very valuable tools. A preliminary view of these two analyses is provided in Section II of this report.

With these analyses in hand, the third and most critical step will be for the federal and state governments, the medical and legal professions, and the terminally ill and their families to join together in developing those policies which will give the terminally ill more control over medical treatment decisions.

ACKNOWLEDGEMENTS

The Chairman of the House Select Committee on Aging gratefully acknowledges the assistance of the Congressional Office of Technology Assessment in preparing this report. In particular, Robert Cook-Deegan, Robert Harootyan, and Teresa Myers deserve special recognition for their diligent and timely assistance.

The Chairman also wishes to give a special acknowledgment to Joan Densberger, a law student of Boston College Law School, who supported the Committee staff by compiling and drafting major sections of this report.

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SECTION I. ISSUES SURROUNDING AMERICA'S TERMINALLY ILL AND THEIR MEDICAL TREATMENT.

BACKGROUND ON MEDICAL TREATMENT FOR THE TERMINALLY ILL.

Death is not a subject limited to the elderly. However, elderly persons in our society are in a uniquely vulnerable position because of factors such as advanced age, constrained financial resources and physical incapacity, to mention but a few. These factors, alone or in combination, can severely impair elderly persons' abilities to manage and care for themselves even when they desire and are physically able to do so. Also, many elderly persons experience a period of prolonged chronic illness before dying, unlike an acute medical crisis or trauma situation more common in younger patients.

Under these circumstances, terminally ill persons should maintain control over their own lives to the greatest extent possible. This includes the freedom to make their own medical treatment decisions. Yet, we want to know that the decisions they make are truly their own, and not the product of external forces. These forces might include financial pressure either on their families or their physicians and hospitals.

The control over medical treatment decisions remains a controversial issue. Many people are most concerned about the terminally ill person's lack of a right to have medical treatment. Many other people are most concerned about the terminally ill person's right to refuse medical treatment. Given this lack of agreement, these decisions are and should remain very personal decisions. Clearly, the terminally ill need to be protected -- they need both the right to have medical treatment and the right to refuse medical treatment. *

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* Under current law, people do have the right to refuse medical treatment. However, current law does not guarantee that people have the right to have medical treatment.

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CONFLICTING PRESSURES. In our efforts to help terminally ill persons maintain decision-making control, we must keep in mind that improvements in medical technology have given us a much greater ability to sustain life than in the past. However, this same medical technology has created very difficult choices for dying persons, their families, their physicians and society as a whole. Tragically, the dying person is the one who is being trapped in the middle -- trapped in a "Catch-22" situation.

On the one side are the physicians with an inherent desire to sustain life. Physicians face a dilemma as they fight to keep the dying person alive while also trying to respect a dying patient's decision to refuse medical treatment. On the other side are the national policy-makers who continue to cite the high cost of caring for the dying. Some policy-makers imply that the dying have a duty to die and make way for the living.

ETHICAL CONSIDERATIONS. Under the stressful circumstances of terminal illness, a shift in decision-making power from terminally ill persons to other decision-makers tends to occur. The decision-making freedom of terminally ill persons may be subtly subsumed by others in carrying out what surrogate decision-makers perceive as their role. In some instances, this shift in decision-making occurs outright due to a court pronouncement of mental incompetency and appointment of legal guardians for the terminally ill.

The consequences of such infringements on decision-making power are drastic. Terminally ill persons may no longer have control over the most personal experience they have faced in their lives -- their own death. To the extent possible, society may want to honor the desires of terminally ill persons who want or do not want a protracted existence on artificial life-support systems. However, we must also protect the terminally ill from a coerced, involuntary decision whether it is to have or to refuse medical treatment.

COMPETENCY CONSIDERATIONS. The right to consent to or refuse treatment is a legal and ethical right of all mentally competent patients. This basic right continues to exist even when the patient subsequently becomes mentally incompetent. However, there is a legal distinction between the competent and incompetent patient insofar as their rights with respect to medical treatment. If a patient has been determined incompetent, someone else must make treatment decisions on behalf of the patient.

Because of this legal distinction, the mental competency of terminally ill persons to make decisions about their medical care is a central issue in medical decision-making. Determinations of incompetence deprive terminally ill persons of their freedom to exercise their right to consent to or refuse medical treatment. For the elderly patient who, for example, has been placed in a hospital or nursing home, is heavily medicated and is frightened by unfamiliar impersonal surroundings, the issue of competence is glaring.

Because of the potentially devastating consequences that determinations of incompetence have on the liberty of terminally ill persons, there is a need for a consistent and uniform approach in competency determinations. One legal standard receiving growing support is that of whether patients, including terminally ill persons, understand and appreciate the nature and consequences of their decisions regarding medical care. There is still much controversy, however, surrounding the following questions:

1) Who is questioning the patient's competency and why?
2) In what forum should competency determinations take place -- the hospital or the court?
3) Who should perform the competency determination?
4) What should be the consequence of a determination of incompetency?

SURROGATE DECISION-MAKING CONSIDERATIONS. If terminally ill persons are determined to be mentally incompetent to make treatment decisions, the crucial questions become:

1) How should surrogate decision-makers be designated?
2) Who should be the surrogate decision-makers (e.g., family member, friend, attorney)?
3) What decisions may they make (i.e., what forms of medical, treatment can the surrogate consent to or refuse on behalf of the patient)?

Terminally ill persons who have no one to act on their behalf in making medical treatment decisions present a special problem. One response by the States has been to provide for public guardianships appointed by a court.

Public guardianships have received some criticism due to the potential conflict of interest when public agencies have been appointed as guardians of wards, but are simultaneously providing services to the wards under restrictive cost constraints. For purposes of accountability, if public agencies are appointed as public guardians, the appointments should be carefully and narrowly circumscribed to the power to act only in the specific situations in which the wards are incapable of acting on their own.

ADVANCED DIRECTIVE CONSIDERATIONS. More and more attention is focusing on increasing the terminally ill person's control over their final medical treatment decisions. There is a growing push to get the public to think ahead and make some type of advanced directive. These advanced directives may be a "living will" (more appropriately termed a "natural death declaration"), a durable power of attorney or some other form of advanced directive.

The various legal devices that exist, such as the durable power of attorney and the "living will", may serve to enhance the ability of the terminally ill to have their desires carried out in the event that they are hospitalized and become mentally incompetent to make their own treatment decisions. However, since some of these mechanisms have not been tested in the courts, their application to the context of medical treatment decision-making remains questionable.

States are wrestling with various approaches to enable people to make an advanced directive. As of 1985, 35 States and the District of Columbia have enacted legislation variously termed "natural death" acts or "living will" statutes. While progress is being made by the States, there is still much to be done. As one example, the lack of uniformity and reciprocity among states with similar "advanced directives" statutes leaves in doubt the enforceability and effectiveness of an advanced directive executed in a State different from that in which terminally ill persons are hospitalized.

While executing an advanced directive is certainly to be encouraged, there is some question as to how many people will actually execute an advanced directive. Even today many people do not plan ahead and die without any type of ordinary will. In the case of persons who have always been incapacitated, there is no opportunity to make an advanced directive. In the case of the poor, the cost of executing an advanced directive is one more expense they probably cannot afford.

OTA STUDIES ON DEMENTIA AND LIFE-SUSTAINING TECHNOLOGIES.

In the course of the House Select Committee on Aging's examination of the plight of America's critically and terminally ill persons, we saw the need for an indepth assessment. The Committee, along with several other House and Senate Committees, requested that the Office of Technology Assessment (OTA) conduct two major studies. The first study is on dementia. The second is on life-sustaining technologies. A preliminary view on these two studies is provided in Section II of this report.

The first OTA study is entitled "Disorders Causing Dementia." This will cover a range of issues from research on the causes of dementia to the legal, financing, social and ethical implications for the victims, their families, and society as a whole. Since certain forms of dementia, most notably Alzheimer's, are debilitating and terminal, this study will play an important role in examining the issues surrounding dying with dignity.

OTA is also engaged in a second study which is entitled "Life-Sustaining Technologies and the Elderly." This second study focuses on developments in life-sustaining technologies. The study also examines the legal, financing, social and ethical implications of these technologies for the elderly and the non-elderly. As medical science continues to advance its ability to sustain life, new questions will arise as to how to use these technologies, how to pay for them, what their impact is on the quality of life, and what are the rights of the terminally ill to refuse or require their use.

The Committee looks forward to learning from these two OTA studies. However, we also recognize that they will not be available for another year. In the interim period, we must continue our efforts to better assist the terminally ill.

CALL FOR ACTION ON BEHALF OF THE TERMINALLY ILL.

As described above, America's terminally ill are trapped in a tragic "Catch-22." While some policymakers pressure the terminally ill to make way for the living, physicians and other health care providers fight to keep the terminally ill alive. All parties need to accept that the terminally ill should have both the right to have and the right to refuse medical treatment. The terminally ill should be free to exercise both these rights without undue pressure.

Though we have much to learn about how best to relieve the pressures, enough is known so that we can better help the terminally ill. Based on an initial review of the problem and of the available solutions, I am recommending the following actions:

Societal pressure to contain health care costs should not be applied to the terminally ill. They already face incredibly difficult decisions with respect to refusing or requiring medical treatment. The victims, in this case the terminally ill, should not have to carry the extra burden of society's desire to contain health care costs.

Catastrophic out-of-pocket health costs for the terminally ill should be limited so that they do not create undue financial pressure on the terminally ill or bankrupt the family. Currently, the out-of-pocket cost burden on the terminally ill and their families can be astronomical and can result in decisions to refuse medical treatment that are not in the best interests of the terminally ill person.

All States should have available legal mechanisms to enable people to make advanced directives with respect to having or refusing medical treatment. In addition to enacting basic legislation, States should address the lack of uniformity and reciprocity currently existing across States and affordability and accessibility for the poor and near poor.

In determining the competency of patients, including terminally ill persons, to consent to or refuse medical treatment, their rights should be carefully protected. Much hinges on the determination of a terminally ill person's competency or incompetency. Since decision-making power, especially in the absence of an advanced directive, for a terminally ill person may be lost quickly and the consequence may be irrevocable, it is critical that competency determinations be carried out in a manner which serves the best interests of the terminally ill person.

For those terminally ill persons who are not competent to make medical treatment decisons, the courts should provide continued oversight of the designated surrogate decision-maker. In making decisions on behalf of a terminally ill person, many competing financial, ethical and societal interests may try to influence treatment decisions. As a result, the courts need to closely monitor the actions of court appointed surrogate decision-makers.

Physicians, nurses and hospitals should be sensitive not only to terminally ill persons' request to have life-sustaining medical intervention but also to their request to refuse medical treatment. No one wants health care providers to reduce their commitment to care for and sustain life in their patients. However, there is a need to balance that commitment with the commitment to provide the medical treatment that is best for the patient, as defined by the terminally ill person or their designee.

A "bill of rights" for patients, including terminally ill persons, should be affirmed legislatively; a nationwide public education program should be developed by federal and state governments to educate the public as to what are their rights with respect to medical decision-making. Though many rights of terminally ill persons may be clearly understood by lawyers and physicians, this is far from the case for the terminally ill and their families. There is a great need to make the public more aware of what are the rights of terminally ill persons and what are the options for exercising those rights.

Now is the time for federal and state governments to relieve the cost-related pressures on terminally ill persons and to give them the legal vehicles which will give them adequate control over their final days. Now is the time for physicians and other health care providers to be more sensitive to and supportive of the final wishes of America's terminally ill.

SECTION II. ISSUES SURROUNDING THE IMPACT OF LIFE-SUSTAINING TECHNOLOGIES AND DEMENTIA ON MEDICAL TREATMENT FOR THE TERMINALLY ILL. *

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* This section was prepared by the Congressional Office of Technology Assessment at the request of the Chairman of the House Select Committee on Aging.

MRS. A

Mrs. A is an 82 year-old woman who has been in a hospital intensive care unit for 4 weeks following a stroke. A ventilator is being used to maintain her breathing. Intravenous nutritional support and hydration are being provided since she cannot eat or drink while on the ventilator. Mrs. A cannot speak because of the ventilator and cannot write due to paralysis caused by the stroke. The hospital staff and her family have noticed that she is much more alert and responsive now than she was immediately following the stroke. They believe she usually understands what is said to her and that she is aware of her physical condition.

Mrs. A's doctor believes that her condition has stabilized and that she will probably need the ventilator for the rest of her life. The doctor has discussed this with Mrs. A's only daughter, and the daughter and several other relatives have talked to the hospital social worker about finding a nursing home that will take Mrs. A. Mrs. A's sister, whom she has lived with for many years, refuses to take part in the family discussions. She says that Mrs. A told her many times that she did not want to be kept alive "on machines". The sister and a nurse on the evening shift say that they asked Mrs. A if she wanted the ventilator removed even though it meant she would die. She nodded yes. Because Mrs. A has no written document to support her wishes, the hospital administration will not allow the discontinuance of the ventilator or the intravenous nutritional support.

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Mrs. A, however, cannot remain in the intensive care unit because the bed is needed for a more critically ill patient. She can be temporarily transferred to a regular medical unit, but the cost of her treatment has already exceeded what Medicare will pay the hospital for treatment of her condition, and the hospital administration is urging the doctor to make plans for discharge. The hospital social worker has contacted several nursing homes but has been unable to locate one nursing home that is willing to take a ventilator-dependent patient.

Each day in the United States, growing numbers of elderly patients, their families, and health care providers are confronted with dilemmas concerning life and death decisions. At the request of the House Select Committee on Aging and the Senate Special Committee on Aging, the Office of Technology Assessment (OTA) is undertaking a study of "Life-Sustaining Technologies and the Elderly." *

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* The full report on "Life-Sustaining Technologies and the Elderly" will be completed in May, 1986 and published, in Summer 1986. For additional information, contact Robert A. Harootyan, Project Director (202/226-2090).

The requests for the assessment reflect growing public concern about increasingly complex situations and decision-making dilemmas exemplified by the case of Mrs. A and her family. The exact wishes of the patient are difficult to discern since no written advance directive or other type of legal instrument is available. Yet even with such a document, precise descriptions of the specific circumstances and conditions are required to be certain that a patient's desires to not receive aggressive life-support treatments are clearly understood. Given any doubt about a patient's wishes, health care decision-makers are most likely to choose aggressive treatment. At the same time, the ability to predict the outcome of such treatment is more difficult in critically ill elderly patients, who are likely to have multiple conditions that make recovery more questionable.

IMPLICATIONS OF IMPROVEMENTS IN LIFE-SUSTAINING TECHNOLOGIES. These dilemmas are expected to grow in number and complexity. Recent technological advances in the treatment of chronic diseases and acute illnesses, combined with greater access to such care, make it possible to keep alive growing numbers of persons who would not have survived in decades past. These advances, however, are accompanied by complex legal, ethical, and financial issues concerning the definition of death, patient's rights, surrogate decision-making, quality of life of the critically ill, appropriate use of life-sustaining technologies, and the influence of economic considerations on the provision of expensive and extensive health care treatments.

Indeed, some studies indicate that almost 30 percent of Medicare outlays are made for care of older Americans within their last year of life. Other research, however, has shown that about one-half of all elderly Medicare beneficiaries with high-cost reimbursements survive and are discharged from the hospital. As these life-sustaining technologies become more available and increasingly feasible for use at home, questions of financial burden and the ability of individuals and society to pay for long-term health care arise.

The OTA assessment examines these technological advances and their implications for the health care of older Americans. The requesting Committees of Congress expressed concern about protecting patients' rights in decision-making regarding the use of life-sustaining technologies and the extent to which aggressive intervention should be given. At the same time, the committees expressed concern about the Federal Government's role in ensuring equal access to life-sustaining technologies in the face of growing economic pressures to reduce the public costs of health care under the Medicare and Medicaid programs.

On the one hand, a fundamental concern is the need to ensure that quality of life and quality of care for the elderly are not jeopardized by federal cost-containment efforts. On the other hand, congressional concerns include the need to preserve the autonomy of elderly patients and to assure their rights to choose when and to what extent life-sustaining technologies should be used. Above all else, the Committees want to be sure that federal health care policies and reimbursement systems do not discriminate against elderly patients through policies that use age-based criteria to limit access to or reimbursement for health care services. Currently, 37 percent of all costs for health care of the elderly are paid out-of-pocket. Any increase in such direct costs to the elderly could influence the willingness of some to seek assistance or to desire continued aggressive intervention.

ISSUES RELATED TO THE MAJOR LIFE-SUSTAINING TECHNOLOGIES. The OTA assessment focuses on five technologies and procedures that are most relevant to the concerns expressed by the requesting Committees. Each technology reflects different aspects of the issues concerning appropriate use of life-sustaining technologies in the elderly.

Renal dialysis is a required treatment for persons suffering from chronic renal (kidney) failure. These patients would die without periodic (usually every other day) dialysis treatments that are provided in hospitals, outpatient clinics, or -- for some patients -- at home. Dialysis is fully reimbursed by the Medicare program, which has witnessed a dramatic increase over the last decade in the number of patients receiving such care. Studies indicate that elderly patients derive considerable benefit from the treatments, significantly improving both the number and quality of years added to their lives. Some indications exist, however, that difficult decisions are made on occasion to withdraw or withhold dialysis for some types of elderly patients. The OTA assessment will attempt to discern the factors that lead to such decisions.

Another technology is prolonged mechanical ventilation, a procedure required for patients who are unable to breath independently. Ventilator-dependent patients may require continuous support, or assistance for only part of a day, depending upon the illness. In the case of Mrs. A, continuous ventilation was required because the stroke greatly diminished her ability to breath. The mobility of most ventilator-dependent patients is greatly limited, although new technologies now permit some patients to use wheelchairs along with portable ventilator units. A high degree of supportive care is required for ventilator patients, whose respiration must be monitored and airways continually checked and cleaned.

An additional life-support technology for Mrs. A is nutritional support through intravenous delivery of liquid nutrients. Mrs. A's stroke and consequent ventilation mean she cannot swallow foods or liquids. Her only source of sustenance is by intravenous feeding. Although this technology is portable and can be used in non-hospital settings, most nursing homes avoid admitting such patients. Nutritional support therapy requires expertise and added staff time to administer and monitor, thereby increasing personnel and other costs. In addition, very few nursing homes have the staff or the willingness to care for ventilator-dependent patients. As noted in the case of Mrs. A, few places exist outside the hospital where she can receive the level of care required.

The fourth technology being investigated by OTA is resuscitation. More than the previously mentioned forms of life-support, resuscitation involves specific decisions about treatment and how aggressive such treatment should be. Decisions to resuscitate are often guided by the severity of the illnesses the elderly patient has, as well as a clear understanding of the patient's wishes regarding resuscitation. The diminished "physiological reserve" of many critically and terminally ill elderly patients creates additional dilemmas in deciding whether or not to resuscitate. A successful resuscitation in such patients can also result in broken ribs, punctured lungs, or other complicating problems. These dilemmas confront health care providers on a daily basis.

The fifth technology being studied is the use of antibiotics in the elderly, especially those who are critically or terminally ill. Such individuals are particularly susceptible to infection, yet antibiotic therapy is often successful. Pneumonia was in earlier periods called "the old man's friend" because of the quiet death it brought. Today, many forms of pneumonia that were once life-threatening to the elderly can be effectively treated with aggressive antibiotic therapy. Decisions to use antibiotics to treat infections are, however, often made in light of the other conditions from which an elderly patient suffers. Again, patients, families, and health care providers are increasingly faced with life and death decisions that must weigh the degree of pain and suffering from competing illnesses that confront the elderly patient.

CONCLUSION. The OTA assessment of "Life-Sustaining Technologies and the Elderly" is reviewing these technologies and providing information on the legal, ethical, and training issues that have accompanied the availability of these increasingly sophisticated interventions. The assessment investigates the influence that the patient's age, mental status, physical condition, attitudes, and concerns about quality of life have on the decision-making process. It also reviews the influence that cost-containment efforts might have on access of the elderly to health care in general and to life-sustaining technologies in particular. Finally, the OTA assessment projects what the "next generation" of life-sustaining technologies may be and the implications they will have for an increasingly aged population in the United States.

MR. A.

Mr. A is a 70-year old man who has developed pneumonia while living in a nursing home. The physicians, nursing home administrators, nurses, and aides are now considering whether to transfer him to a local hospital for treatment. His wife died several years ago. His daughter, who visits him once a month, is not sure whether he should be treated. His son, who resides in an adjacent state, does not want him treated.

Mr. A has been in the nursing home for two years because he suffers from Alzheimer's disease. He lived with, and was cared for, by his daughter in a town 20 miles away until he began wandering out of the house and getting lost at night. Mr. A's nursing home care was initially paid for out of his savings, until his assets were depleted after nine months. He was then admitted into the Medicaid program in his state, which now pays for his care.

This fictional case illustrates many of the dilemmas that arise in the care of patients suffering from dementing disorders. What is death with dignity for a patient like Mr. A? Who should decide whether to transfer Mr. A to the hospital? Should he receive antibiotic therapy? Should his diminished ability to think, comprehend, and communicate clearly be considered in the decision to treat him? Are there programmatic or financial barriers that influence care decisions?

More than 750,000 patients like Mr. A, suffering from disorders causing dementia, currently reside in nursing homes in the United States. Issues surrounding such patients are difficult and complex to resolve, but are receiving increased public attention. The legal, medical, social, and financial aspects of public policy relating to such patients are addressed in the ongoing OTA assessment of "Disorders Causing Dementia." *

LEGAL ISSUES. Who should make the decision about whether to treat Mr. A? The courts and caregivers must attempt to determine what the patient would have wanted in this situation. This determination, however, is fraught with ambiguities, conflicts of interest, and legal uncertainties. If, for example, the son or daughter had been declared the legal guardian or conservator, then this would give an indication of who might be consulted first. However, the court appointment of a conservator or guardian may not reflect Mr. A's preference. In addition, it is not clear that guardianship carries with it the undisputed right to make critical medical decisions on behalf of the patient.

If Mr. A had an advance directive, such as a "living will" or durable power of attorney, that might also yield clues as to his desires. However, advance directives have varying degrees of legal standing, and may or may not cover a patient's particular situation (e.g., whether to treat with antibiotics).

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* This OTA project will be completed in July, 1986. The staff contact at OTA is Robert Cook-Deegan, M.D. (202/226-2034). The project addresses many issues in addition to those noted in this background document, including federal policies on biomedical research and provision of long-term care for patients with dementia.

MEDICAL CONSIDERATIONS. In addition to the legal ambiguities, there is also tremendous medical uncertainty. A physician cannot predict whether Mr. A will live for a month, a year, or a decade if he is treated. He can predict that his Alzheimer's disease will progress but cannot determine the rapidity of deterioration with any accuracy. Furthermore, no health professional can determine Mr. A's assessment of his own quality of life.

Uncertainty also surrounds the antibiotic treatment itself. Optimal medical treatment would include admission to the hospital, multiple laboratory tests, evaluation of other medical problems, and treatment with one or more antibiotics that might or might not cure the pneumonia. Each step in this process has its own sources of error and risk, which add up to medical uncertainty about whether to treat the patient.

If Mr. A leaves the nursing home for the hospital, he may lose his bed at the nursing home. Difficulty in placing him back in a nursing home from the hospital may make the hospital reluctant to admit him. At least three factors would make Mr. A a relatively unattractive candidate for admission back into a nursing home. First, he is covered by Medicaid which pays less than most private pay patients. Second, he suffers from dementia, and many nursing home personnel consider the care of such patients difficult. Third, the mental symptoms due to his Alzheimer's disease could lead to his classification as a 'mental' patient. If more than half the residents of a nursing home are 'mental patients,' then the home risks loss of certification for Medicaid payment. While recent changes in Medicaid regulations specifically state that Alzheimer disease and related disorders are not 'mental' disorders, misclassification of patients based on their symptoms can still occur, and implementation of the new regulations is incomplete.

FINANCIAL FACTORS. Mr. A's nursing home care is now paid for by both the State and Federal Governments through the Medicaid program. Federal outlays for nursing homes were $12 billion in 1983, of which an estimated 50 percent were for patients with dementing conditions. States paid a roughly equal amount.

If Mr. A were admitted to the hospital, his medical care there would likely be borne by a combination of Medicaid and Medicare. Under Medicare, the hospital would receive a fixed payment to treat Mr. A's pneumonia (the amount would be determined by the diagnosis of pneumonia). This means that the hospital gets the same amount regardless of the number of tests administered and whether or not he is effectively treated. Under Medicaid, how the hospital was paid would depend on his state of residence. In some States, the hospital would be paid for individual procedures and treatments; in others it would receive prospective payment, either according to diagnosis (like that under Medicare) or through fixed monthly or annual payments for each patient. If Mr. A were covered under Medicare, the Medicaid payments would pick up most costs not covered under Medicare.

The rapid increase in costs of health care have lead to a growing focus on cost containment. Both the Federal and State Governments are searching for ways to limit escalating budget outlays for health care. Will such concern for budget austerity lead to constraints on whether patients like Mr. A are treated? Such constraints could be due to limited payments for certain diagnoses or procedures, or could follow from financial difficulties and consequent changes in hospital policies over the long run.

For patients like Mr. A, there are several possible problems with prospective payment systems like that now in the Medicare program. First, a hospital may have disincentives to admitting him if he is deemed likely to develop complications or require extensive evaluation of secondary medical problems. The disinclination to admit him derives from the fixed nature of the payment for his primary diagnosis of pneumonia, which would not pay for such complications or extra tests except by resort to a special mechanism that requires documentation and extra paperwork. Second, Mr. A may not be admitted if he is deemed likely to be difficult to discharge, either to a nursing home or elsewhere.

PERSONAL AND SOCIAL VALUES. All decisions about medical care are made in the context of predominant social and personal values. These values can be expressed by the patient (in Mr. A's case through knowing his past views), his family, physicians, nurses, aides, social workers, and administrators.

Social values vary from 'treatment at all costs for all patients' to concern that public funds not be spent to unnecessarily prolong the dying process for those who are hopelessly ill and are perceived to have a low quality of life. These values are incorporated into Government health care programs. The problems in admission to hospitals and nursing homes faced by patients with dementia listed above, for example, are due to decisions made and included in public health care programs. The institutional practices of nursing homes, hospitals, and other health care institutions also reflect social values.

Each individual brings his or her own biases and professional perspective to decisions about treatment. Physicians may have one opinion, family members another, and aides involved in daily care yet another.

CONCLUSION. Decisions about medical treatment, acute health care, and long-term care are complex and involve many social values, distinct and often conflicting personal views of those involved, and are made in an environment increasingly focused on costs. Such decisions are difficult for those who are aware of their own plight, and even more complicated for those affected by a dementing disorder.